

Although including children in trials has benefits, technical, practical, and ethical problems remain.<sup>6</sup> Technically it will be necessary to develop further non- or minimally invasive techniques for pharmacokinetic and pharmacodynamic assessments. Pharmacodynamic assessments are required to determine accurate dosage even in clinical trials. This is especially important in children whose metabolism of drugs and sensitivity of end organs to them vary considerably with age and stage of development. Practical difficulties arise from the small number of children with specific disorders, the need to study different ages, the formulation of drugs, and problems of recruitment.

Ethically, the obligation to act in a child's best interests entails protecting children from both the potential risks of research and the harms produced by the use of inadequately tested drugs, as well as respecting their autonomy. To satisfy these requirements drug trials should be scientifically and socially valid, adequately powered, of favourable risk-benefit ratio, subject to independent ethical review and informed consent, and conducted to an appropriate standard.<sup>7</sup> But inevitably, pharmaceutical studies carry risks of physical or psychological harm that may be difficult to quantify. Acceptance of some risk is necessary for therapeutic advances to occur, for example, in the treatment of acute lymphoblastic leukaemia.<sup>8</sup> Difficulties in recruitment may mean that studies lack the statistical power to answer the questions they pose. In contrast large studies are expensive and, if commercially sponsored, may tend to favour the drug tested. Commercially funded research understandably includes drugs that are likely to have high volume sales—for example, antibiotics—or high unit costs, such as surfactant.<sup>8</sup> Research ethics committees must assess all these factors but do need sufficient expertise in paediatrics to do so safely and effectively.

Obtaining adequately informed voluntary consent for participation in a drug trial requires the children's assent or consent, commensurate with their understanding and experience, with or without the permission or consent of their parents.<sup>8</sup> Imparting sufficient, comprehensible information to distressed parents and ill children is difficult and leads to questions of their competence to make decisions. Understanding of such terms as randomisation, trial, and placebo may be imperfect.<sup>9</sup> Parents may accept drug treatment as being the only hope for their child irrespective of the risks entailed; they may feel obliged to researchers and

believe that refusal to enter a trial will compromise their child's treatment.<sup>4</sup> Doubt therefore exists whether truly informed consent is possible, especially in acute life threatening situations.

These factors and issues raised by the Bristol and Alder Hey inquiries and the Griffiths's report have created a climate in which the testing of medicines in children poses difficulties. Overcoming them is essential if children are to benefit from the development of safe effective drugs. One possible solution would be to introduce legislation such as that in the United States. But such legislation may not in itself lead to a greater number of children being enrolled in drug trials or deal with the difficulty in obtaining sufficiently informed consent. Moreover, the exclusivity provision has been criticised as benefiting the interests of companies rather than children.<sup>4</sup> An alternative, but long term, strategy is the greater involvement of children and their families in the planning and implementation of research projects, which should have notable educational impact.<sup>10</sup> This approach could both increase recruitment and satisfy the criteria for informed consent.

In the meantime, those who prescribe for children should use drugs that are licensed or accepted as offering the best possible prospect of benefit by a responsible body of medical opinion. Equally they have a duty of advocacy on behalf of children, supporting the therapeutic orphans who, like fictional character Oliver Twist, are saying: "Please sir, we want some more."

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## Racism and health

### *Antiracism is an important health issue*

**D**iscussion of racial discrimination in medicine has concerned mainly recruitment and career development.<sup>1,2</sup> This has overshadowed a growing literature showing an association between racism, morbidity and mortality.<sup>3-7</sup> Racism may be aetiologically important in the development of illness.

Racism stems from the belief that people should be treated differently because of a few phenotypic features. Racism can manifest as individual or group

acts and attitudes or institutionalised processes that lead to disparities. Racism is common: in one national survey in the United Kingdom, 25-40% of participants said they would discriminate against ethnic minorities; an estimated 282 000 UK crimes were racially motivated in 1999; and a third of people from ethnic minorities constrain their lives through fear of racism.<sup>8,9</sup> Disparities between ethnic minority and majority groups in housing, education, arrests, and



court sentencing are believed to be due to racism, not simply to economic forces.<sup>8 9</sup>

Cross sectional studies in the United States report associations between perceived racial discrimination and hypertension, birth weight, self related health, and days off sick.<sup>3 4</sup> In a recent study from the United Kingdom victims of discrimination were more likely to have respiratory illness, hypertension, a long term limiting illness, anxiety, depression, and psychosis. People who believed that most companies were discriminatory were also at increased risk of mental illness.<sup>5</sup>

Racism may be associated with illness at an ecological level.<sup>6</sup> Kennedy et al found that a 1% increase in racial disrespect in a US state was associated with an increase of 350.8 per 100 000 in "black" all cause mortality.<sup>7</sup> Most of the studies have, however, been secondary analyses, and racism has often been poorly measured and the ability to allow for confounders limited.

One prospective study in the literature adds support to the hypothesis that discrimination affects psychological health. In a study of over 4800 residents of Maastricht who screened negative for mental illness and paranoid traits at baseline, those who said that they had suffered from discrimination were twice as likely to develop psychotic symptoms in the following three years.<sup>10</sup>

Stress mediated responses in the neuroendocrine and immune systems have been considered possible mechanisms for the effects of racism on health.<sup>11</sup> Racist acts may be acute stressors and the perception of society as racist and the effects of racism on self perception chronic stressors.<sup>11</sup> But the literature is sparse. To date the effects of racism at a community level—such as the production of alternative economies (for example, gang culture) or the creation and maintenance of socioeconomic disparities—have rarely been modelled as part of its effects. The effects of racism on future generations—for example, on the long term impact of having a parent with an illness—have not been addressed either.<sup>11</sup> The effects of racism are modified by individual coping styles and expectations,<sup>4</sup> community structure and response to racism, historical and macropolitical factors.<sup>11</sup>

Considering racism as causative is an important step in developing the research agenda and response from health services. It moves the discussion away from recruitment and access and towards prevention and the impact of societal structures on rates of illness. The investigation of specific risk factors for illness in ethnic minority groups may be vital if we are to develop equity in efficacy of treatment. For example, is the poorer response to antihypertensive treatment in African-Caribbeans due to biology or is it a reflection of the role of perceived racism in its development and persistence? Investigation of racism's pathophysiological, cognitive, or psychophysiological correlates may offer new avenues for treatment and more efficacious management. Developing a deeper understanding of possible links between racism and health is a prerequisite for initiatives to decrease impact at a community and individual level.

Despite general agreement that racism is wrong, no concerted political effort has tried to decrease its prevalence. Granted, if the Race Relations Amendment Act were enforced it could decrease institutional racism in public bodies, but it is an isolated act that

should be seen in the context of other acts and government rhetoric considered to harm race relations (for example, the current discourse on asylum) and the widespread nature of racism.<sup>12</sup>

Public health is the art and science of preventing disease, prolonging life, and promoting health through the organised efforts of society. One of the chief responsibilities of public health medicine is fostering policies that promote health. I argue that countering racism should be considered a public health issue. The lack of a concerted research and public health effort means that in the United Kingdom the science of investigating the effects of racism on health and the development of preventive strategies are in their infancy. It is tempting to argue that it is not for doctors to be involved in areas that are so political. The real question, however, is best laid at the doors of those who would prefer not to take on this challenge. How can we have equity in health if one of the major possible causes of illness in minority ethnic groups in the United Kingdom does not have a dedicated research effort or prevention strategy?

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## What is a good death?

The *BMJ* is devoting a special issue to the topic of a good death, which will be published in July 2003. We welcome reports from all over the world and invite submissions of original research, editorials, educational articles, debate pieces, personal views, pictures, and art. All submissions should be made to [submit.bmj.com](mailto:submit.bmj.com) and will go through the usual peer review process. The guest editor for this theme issue is Peter Singer, and the editorial contact is Jocelyn Clark ([jclark@bmj.com](mailto:jclark@bmj.com)). The closing date for submissions of original research articles is 30 January 2003.